

A CAREGIVER'S GUIDE TO EMBRACING RESPITE ACROSS THE LIFESPAN



IDAHOCAREGIVERALLIANCE.COM

A SPECIAL NOTE TO YOU, THE CAREGIVER

Caregiving is a special journey. It is our hope that this guide will help you, the family caregiver, identify as a caregiver and recognize the value you offer to your loved one, to your community, and to our state; coming away with a few new tools to help you take a well-needed break.

Please note that this guide is intended for caregivers across the lifespan and is to be consumed at your pace. Read, make notes, step away, and come back, when you need.

ACKNOWLEDGEMENT

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IN PARTNERSHIP



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Are you a family caregiver?

As expressed by Rosalynn Carter, “there are four kinds of people in the world: those who have been caregivers; those who currently are caregivers; those who will be caregivers; and those who will need caregivers.” Caregiving encompasses many responsibilities and has many different faces. The care you provide may range from a trip to the grocery store or a medical appointment, to 24/7 care involving medication administration, wound care, or other complex medical services. Your caregiving role may last a few months or a lifetime, and although these responsibilities are taken on willingly and with love, they challenge your well-being.

If your tasks include:

- caring for a medically fragile child or a child with a disability,
- making phone calls to check in on a loved one,
- helping someone with household chores or making meals,
- providing emotional, spiritual, or financial support,
- helping someone make healthcare decisions and coordinate care

Then you probably need a break once in awhile and this guide is for you.



CHAPTER 1

Respite is a Fancy Word for Taking a Break (WebMD)

DESCRIPTION

Respite allows you to take time off from caregiving duties while someone else cares for your child, your spouse, your parent, your grandparent, your neighbor; your loved one. Depending upon your resources and the local programs offered, the length of time respite care lasts is entirely up to you. You can leave for an afternoon, a weekend away, or even a week's vacation. Most folks schedule a break lasting 2-3 hours to provide consistent, reliable care, allowing the caregiver to plan activities outside of the home.

Source: paraphrased from [What is respite care from Care.com](#)



Acknowledging that you need a break is one thing.
Knowing how to take a break and what to do during your respite break is another thing altogether.

OTHER NAMES FOR RESPITE

PCS, attendant care, companion services, group based, taking a break

LEARN MORE ABOUT RESPITE

ABC's of Respite: A Consumer Guide for Family Caregivers ([ARCH National Respite Network and Resource Center](#))

BENEFITS FOR THE CAREGIVER AND CARE-RECEIVER

For the caregiver, respite:

- allows time to rest and rejuvenate so you may return to your caregiving duties refreshed and with a renewed sense of resolve.
- reduces the stress inherent with caregiving.
- helps boost your immune system if taken at regular intervals.
- improves your patience.
- restores your energy.
- allows time to focus on other personal matters.
- allows you the time to foster friendships and engage in activities, often easing the symptoms of depression.
- allows time for family and career commitments.
- provides opportunities for vacations and other outings.
- provides you a little distance from caregiving, often helping you return with a new sense of perspective.



Respite also provides benefits for the care-receiver (the person you care for).

- ❑ Caregivers who care for themselves often provide better care to their loved one.
- ❑ Respite provides more variety and new relationships for the care recipient.
- ❑ Respite reduces feelings of social isolation and depression.
- ❑ Respite provides opportunities for growth and development.
- ❑ Respite ensures the care recipient will not be neglected at times when a family caregiver can't be there, so that all their needs are met.

Source: [Platinum-Communities.com](https://www.platinumcommunities.com)

CREATING A VISION FOR YOUR RESPITE PLAN.

1. WHAT'S GOING ON IN MY LIFE?

What you do -

- Who do you care for?
- How much time do you spend caregiving?
- Do you live with the person you care for?

How caregiving impacts you & others -

- How does caregiving impact you, your loved one, and your family as a whole?
- How has caregiving impacted your work-life and social life?
- How has caregiving impacted your physical, mental, and spiritual health?

Your Notes: What do you do and how does it impact your world?

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Example: Being the sole care provider, 24/7, makes me feel cut off from the rest of the world. I don't talk to friends, I resent my family for not helping, and I've gained a lot of weight. I feel tired and depressed a lot of the time.

2. HOW WOULD TAKING A BREAK HELP ME AND THE ONE I CARE FOR? (BE SPECIFIC HERE)

- Benefits for me
- Benefits for my loved one
- Benefits for my friends and family

Example:

For me: reconnect with best friend, exercise, hopefully be less resentful. Feel better about myself.

For loved one: enjoy company, ease feelings of guilt about me being full-time caregiver.

For family: Relief that I am taking a break and getting help. Maybe time for my sister and I to reconnect.

Your Notes: What are the benefits of you taking a break?

ME -

MY LOVED ONE -

OTHERS -

3. WHAT ARE MY SUPPORTS

Part of a successful respite plan is considering the supports you have within yourself and surrounding you. These supports are who you can call or what you rely upon when times are tough. They can be: your spouse or partner, child(ren), grandparents, neighbors, church members, healthcare providers, and support groups.

Your Notes: Identifying your supports

Relationships	Community-based
Personal strengths & assets	What am I missing?

Example: The supports I rely upon most are my children and knowing that they will come over to relieve me if I need to just go for a walk. I would like to build more supports within the community so that I don't have to rely upon my children so much. I could look for support groups and become better at reaching out and asking for help. I could call a friend to meet me for coffee/tea. Sources: [UMKC Institute for Human Development, UCEDD](#) and [Altas of Caregiving](#)

“BY LOVING YOU MORE,
YOU LOVE THE PERSON YOU

-PEGGIE SPEERS, THE INSPIRED CAREGIVER: FINDING JOY WHILE CARING FOR THOSE
YOU LOVE

4. WHAT GROUP RESPITE OPTIONS ARE CURRENTLY AVAILABLE IN MY COMMUNITY? (CHECK OUT PAGE 21 FOR INFORMATION ON WHO TO CALL FOR COMMUNITY-BASED PROGRAMS.)

- What days are they hosted?
- What times are they hosted and how long do they run?
- Do you need to RSVP or just show up?

Example: I notice that the Panhandle Autism Society hosts a parent group, the next one is on Monday between noon and 1:45 p.m. This will be a great way to connect with other parents and at the same time get a little rest.

5. HOW CAN I MAKE SHORT BREAKS HAPPEN?

- What would you do with a short break?
- Who would you spend your time with?
- What needs to be in place for you to take a break?

Example: I would take a water aerobics class with my friend, Gina. I need to have a competent helper who can be at my house from 6:30 – 8:30 am, Monday, Wednesday & Friday. They would need to fix and serve breakfast.

Your Notes: How will you make your short break happen?

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CHAPTER 2

Preparing for Respite

TALKING WITH YOUR LOVED ONE

Talking with your loved one about respite can be daunting. For your loved one it can be difficult, maybe even embarrassing, to accept help from a respite provider. For you, there may be feelings of guilt and worry.



Check out the talking points and strategies below to jumpstart your respite conversation. The goal is to create a shared vision of “good respite.”

1. INVOLVE YOUR LOVED ONE IN THE PLANNING FOR RESPITE.

- Good Vision: Ask your loved one to describe a vision of what good respite care might look like.
- Bad Vision: Ask your loved one to describe what they DO NOT want respite care to look like.

Excerpt from p. 6 “Charting the Respite Guide,” Charting the LifeCourse, developed at [UMKC INSTITUTE FOR HUMAN DEVELOPMENT, UCEDD](#)

Example: Good respite = a middle-aged female who will read to me and not snoop around the house. Bad respite = someone who ignores me and spends most of their time looking at their phone. I do not want a male caregiver or a teenager.

Your Notes: What is the vision of respite you share with your loved one?

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Meeting a new respite provider may be the beginning of a stressful transition period for many of our loved ones.

2. A FRAMEWORK FOR A POSITIVE CONVERSATION

The National Council on Aging Care offers the following tips:

- Don't rush the conversation
- Pick the right place and time
- Focus on your loved one's feelings, fears and desires
- Ask questions to direct the conversation
- Do your homework so you can offer specifics to your loved one
- Involve your primary care physician, clergy or other trusted party to initiate the conversation if your loved one seems resistant

Learn more at [Aging.com](https://www.aging.com).

3. TALKING WITH CHILDREN OR LOVED ONES WITH DEVELOPMENTAL DELAYS

Meeting a new respite provider may be the beginning of a stressful transition period for many of our loved ones.

The Child Mind Institute offers tips to help smooth the transition to respite care.

- Create routines – Routines foster security and comfort
- Preview & countdown – No surprises!
- Give it a soundtrack – Create a “respite song” to help prepare your loved one for the arrival of the respite provider.
- Visual cues – Use a chart or a calendar
- Reward good behavior!

Your Notes: What do you want to cover in your conversation?

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GET SPECIFIC - CREATE A JOB DESCRIPTION

Whether you share it or not, creating a job description will help you articulate your needs.

This table illustrates the building blocks for your job description.

Suggested Criteria	What Yours Might Look Like
Who requires care – infant, toddler, child, teen, adult, senior	Respite caregiver to stay with my 9-year-old son
Experience required?	1-year experience working with special needs children
Experience with behaviors (be as specific as possible)	Stress behaviors include: verbal outbursts and aversion to touch
Condition	Autism with limited verbal skills
Must haves: Examples - CNA, CPR/First Aid, likes pets, non-smoker, light cleaning, meal preparation, personal grooming, language, references, clean driving record, pass criminal background check, drug screening.	Required: CPR/First Aid certification, non-smoker, 3 character references, pass criminal background check, drug screening.
Like to haves: Example - read to client, play games/music, water plants	Preferred skills: enjoy reading stories, playing matching games, taking short walks
Schedule: 3 hours every Tuesday, 1 weekend per month	Schedule: 3 hours every Tuesday, 1 weekend per month



Your Notes: Write your job description

Suggested Criteria	Your Criteria
Who requires care – infant, toddler, child, teen, adult, senior	
Experience required?	
Experience with behaviors (be as specific as possible)	
Condition	
Must haves: Examples - CNA, CPR/First Aid, likes pets, non-smoker, light cleaning, meal preparation, personal grooming, language, references, clean driving record, pass criminal background check, drug screening.	
Like to haves: Example - read to client, play games/music, water plants	
Schedule: 3 hours every Tuesday, 1 weekend per month	

CREATING YOUR CONTACT/INFORMATION LISTS

General Information:
Here's How Your List Might Look

Contacts	Special Info	Food	Activities	Misc.
Family	Medication	Favorite snacks	Reading	Pet name
Medical	Insurance	Allergies	Games	Do not leave pet unattended with son.
Others	House directions: 1. Alarms 2. Stored Items			

Check out these sites for more suggestions

[Agingcare.com](https://www.agingcare.com)

<https://www.agingcare.com/articles/the-emergency-medical-file-every-caregiver-should-create-428239.htm>

[Care.com](https://www.care.com)

<https://www.care.com/c/stories/5769/how-do-i-prepare-for-respite-care/>



Your Notes:

What needs to be on your list?

A series of horizontal dotted lines for writing notes, spanning the width of the page.

CHAPTER 3

Finding Respite Across the Lifespan

PROGRAMS

As mentioned before, respite can look many different ways. Some people find support groups, locating helpful resources, or just having someone else to talk to, as respite. Here is a non-exhaustive list of programs that can help you navigate your respite questions and needs.

2-1-1-Idaho Careline

[211-Idaho Careline](#) can help you locate resources and support as a caregiver, including respite. They can be reached via phone, text, email, and online. Call 211 or 800-926-2588, text 898211 (text your zipcode to this number), email CareLine@dhw.idaho.gov to find out more.

Alzheimer's Idaho

Alzheimer's Idaho, based in the Treasure Valley, is a grassroots group that serves individuals statewide and may be able to help subsidize some respite hours. For information, contact 208-914-4719 or click on the interactive link, [Alzheimer's Idaho](#).

Alzheimer's Association

The national Alzheimer's Association has two chapters for Idaho, the [Greater Idaho Chapter](#) and the [Washington State Chapter](#). Both offer free support groups, a 24/7 helpline, and additional programs and resources for individuals with Alzheimer's disease and their families.

Area Agency on Aging (AAA)

From congregate meals, transportation, and adult protective services, to respite and caregiving classes, your AAA can help guide you. To get assistance, contact the [Area Agency on Aging](#) nearest you.

PROGRAMS CONT.

Certified Family Home Program (Adult hourly care)

Coordinated through the Idaho Department of Health and Welfare, some Certified Family Homes can offer respite services to adults for a few hours a day. Click on [Certified Family Home Program](#) to learn more and find a list of providers in your region. Scroll down toward the bottom of the page until you see "Find a CFH Placement."

Family Caregiver Navigator

The Family Caregiver Navigator program is currently in its pilot stage, serving caregivers within the South West Region of Idaho. This is a telephonic program aiming to reduce the burden on caregiving. Caregivers receive a caregiver-centered plan and are connected with resources available in their community.

Idaho Developmental Disabilities Program

[Idaho Developmental Disabilities Program](#) can help provide services to assist in the care of adults and children with developmental disabilities and can help guide you through your caregiving needs.

Idaho Federation of Families for Children's Mental Health

The [Idaho Federation of Families](#) provides education, support, and advocacy work for families, free of charge, who seek assistance for children or youth with mental health needs.

Idaho Medicaid

Idaho Medicaid can help with respite services across the lifespan. To find out if the one you care for qualifies, contact the Idaho Department of Health and Welfare at 1-877-456-1233. Additional information can be found on the Arch Respite website at [Idaho State Information on Respite Providers or Programs](#).

PROGRAMS CONT.

Idaho Parents Unlimited

[Idaho Parents Unlimited Inc \(IPUL\)](#) aims to educate, empower, support, and advocate for individuals with disabilities and their families. They can help guide you through your caregiving needs.

Idaho Respite Care Voucher Program

The Idaho Respite Care Voucher Program (through BPA Health) is a voluntary program that provides financial relief by issuing payment for respite care services to the primary care giver for services rendered by a provider in the child's natural support system. This allows qualified families of youths with Serious Emotional Disturbance (SED) the opportunity to decompress or tend to important matters with the peace of mind that their child is being cared for by someone the child is familiar with or independent from a provider agency. The result is the reduction of stress and an increase in stability within the family unit. Contact [BPA Health](#) for eligibility criteria and to apply.

KinCare/KinShip Care

For family caregivers who are caring for their grandchild, their niece, their neighbor's child, etc. Resources for being a KinCare provider can be located at [211-Idaho](#), [Relatives as Parents](#), and through your local [Area Agency on Aging](#).

Legacy Corps

[Legacy Corps](#) is a volunteer-powered caregiver support program providing services to caregivers emphasizing the unique needs of veteran and military families. Legacy Corp volunteers provide in-home respite, transportation, resources, and social events for the caregiver and the ones they love.

PROGRAMS CONT.

Medicare

If your loved one receives Medicare, reach out to [Senior Health Insurance Benefits Advisors](#) (SHIBA), with the Idaho Department of Insurance, to see if they are eligible. Their phone number is 1-800-247-4422. If your loved one is dual-eligible (Medicare & Medicaid), they may qualify for some in-home respite services. To find out more, contact the dual-eligible provider your loved one is covered by.

Youth Empowerment Services (YES)

The [Youth Empowerment Service](#) is a system of care formed through state and community partnerships for children and their families who need behavioral health and emotional supports and services. YES services can range from case consultation, crisis intervention, and transportation, to respite care. Contact the [Department of Health and Welfare](#) to find out what services are available in your region.

A Parent's Guide to Respite for Children

[Get Creative About Respite](#) – A Parent's Guide (Connecticut Respite Coalition).

For additional programs that can help you get started,
check out the [Idaho Caregiver Alliance website](#).

Can I get paid to take care of my loved one?

The Idaho Department of Health and Welfare's Certified Family Home Program may be a viable option for those meeting the established criteria. The program requires certification and ongoing training and the person receiving care must qualify for Medicaid. To determine if this is a good fit for your family and if your loved one qualifies, contact the Department of Health and Welfare at (208) 239-6263 or visit the Department of Health and Welfare's [Certified Family Home Program](#) page.

Another method is to become employed by an in-home healthcare provider/home health agency near where your loved one lives and become assigned to your loved one as a client of the agency. Your loved one can pay the agency fees and you would be paid as an employee. This also may be an option if your loved one qualifies for financial assistance through the Idaho Department of Health and Welfare (IDHW). To determine if your loved one qualifies, apply at your local IDHW office. If your loved one qualifies for assistance they may be eligible for an array of services. Click on this link from the Department of Health and Welfare to [Apply for Assistance](#). If the link does not work cut and past the following link <http://www.healthandwelfare.idaho.gov/FoodCashAssistance/ApplyforAssistance/tabid/1554/Default.aspx>.

SCREENING PROVIDERS

It is essential to consider the type of support you or your loved one receives and/or if you will be paying for the respite service privately. Will the person come to your house, or will you drop your loved one off with the respite provider? These circumstances will help you determine which questions you will need and want to ask.

Interview Questions for Independent Respite Care Workers:

- Tell us about your education and/or experience as a respite care provider.
- What are your preferred methods of learning? (e.g.; on-the-job, written or verbal instruction, manual, etc.)
- Why are you interested in providing respite care?
- Describe your strengths. How would you describe yourself?
- Why are you the right person for the job?
- What are your thoughts about families who have children/adults with disabilities or chronic illnesses?
- What would you do if we disagreed about something? How shall we give each other feedback?
- If my loved one had to be taken to the hospital for an emergency, what steps would you take?
- How do you believe difficult behaviors should be managed?
- What would you do if you found a loved one with an open bottle you suspect is poison?
- Are you willing to take my loved one out for activities?
- Describe a difficult problem you've had to handle with a loved one. How did you handle it?
- Tell me about any special training or experience you might have.
- Would you be comfortable with changing diapers in adolescents or adults?
- How would you know if my loved one likes a particular food or activity if he cannot speak?
- Are you willing to have a criminal background check done?
- Do you have CPR, first aid, and/or medication administration training?
- Do you have a valid driver's license?

Questions for Respite Providers/ Agencies:

- How are care providers screened?
- What is the training and level of experience of the care providers?
- Will care providers need additional training to meet specific family needs?
- Will we have the same respite provider every visit?
- How, and by whom, are the care providers supervised?
- What procedures does the program have for emergencies?
- Are families limited to a certain number of hours of services?
- Does the program provide transportation and meals?
- What is the cost of services? How is payment arranged?

Lists courtesy of the Respite Care Association of Wisconsin, [Tips for Hiring a Respite Care Worker...](https://respitecarewi.org/live/wisconsin-respite-care-registry-providers-info/tips-for-hiring-a-respite-care-worker-or-provider-agencies/)
If the link does not work cut and past the following link <https://respitecarewi.org/live/wisconsin-respite-care-registry-providers-info/tips-for-hiring-a-respite-care-worker-or-provider-agencies/>.



CONDUCTING A BACKGROUND CHECK

Seeking out a respite provider for your loved one can be scary. You want to make sure they are getting the best of care, conducting a background check may provide you additional comfort in your choice of respite providers. Educate yourself about background checks. Visit the Department of Health and Welfare's [Criminal History Background Checks](#) page of their site.

- If your loved one qualifies for Medicaid waiver then the Idaho Department of Health and Welfare will conduct this for you.
- If you are a private payer, you will need to pay to have the background check conducted.

Your Notes: What questions do you want to ask?

Your questions	Answers

PREPARING FOR A GREAT FIRST RESPITE VISIT



Involve your loved one as much as possible. Their opinion matters!

- Interview caregivers together. Working together gives your loved one a vote and a sense of control.
- Emphasize the positive! “We are making a new friend.” “Your respite provider is excited to spend time with you!”
- Talk about what the respite provider can do. “Your caregiver loves to read. I think he’s bringing over a few books to see if there’s one you’d like read together.”
- Don’t rush out the door. The first visit is about creating the foundation for a great long-term relationship. Do your best to be sure your loved and respite provider are comfortable and engaged before you go.
- Learn more at [ElderLink.com](http://www.eldercarelink.com/In-Home-Care/How-to-Prepare-for-In-Home-Care-Services.htm) <http://www.eldercarelink.com/In-Home-Care/How-to-Prepare-for-In-Home-Care-Services.htm>

Your Notes: How can I include my loved one as we prepare for the first visit?

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CHAPTER 4

Maintaining Respite

ESTABLISH AND MAINTAIN OPEN LINES OF COMMUNICATION

Communication with your loved one about respite does not stop after the planning phase. Make sure to continue conversations with your loved one well after the first visit. Continued communication will help your loved one feel as much a part of the decision as you, but it will also provide you comfort the next time you schedule a respite visit.

Imagine a respite visit where you can relax and enjoy yourself, knowing your loved one is doing fine.



You know your loved one best. Please encourage your loved one to express themselves through the preferred form of communication, especially when taking on a new venture such as respite.

Pay attention to non-verbal cues & unexpressed concerns

- Physical changes: appearance or mental abilities
- Worries about the loss of the roles they fulfilled in life
- Thoughts about what the future holds
- Concerns about being a burden
- Closed body language or lack of eye contact

Talking with your loved one

- Ask open-ended follow-up questions to the things they say and avoid questions that result in a short yes/no answer. Share your own thoughts and ideas to get the conversation started. Don't be discouraged if your loved one isn't as enthusiastic to talk as you are.
- Avoid phrases that tend to shut the conversation down or seem dismissive. Phrases like "Don't worry about that," or "You'll be just fine."
- Listen more and talk less.
- Repeat back what the person has said to make sure that you understand. Ask for clarification if you aren't sure what they mean.
- Let them know how you plan on helping resolve specific concerns.
- Remain positive and look for small ways to make tasks enjoyable.
- Avoid deep conversations when you are rushed for time.
- Express yourself physically, as well as verbally – A gentle touch can be reassuring.

Learn more at [13 ways to improve your caregiver communication skills.](#)



A caregiver log and feedback from your loved one provides you a good foundation for communicating with your respite provider.

DOCUMENTING OR LOGGING THE VISIT

Clear communication with your loved one is not all that is needed. You'll want to make sure you have a documentation system in place so that your respite provider can jot down what happened during their visit. Creating a log ahead of time will help clarify your expectations for the respite provider and will help you remember what you'd like to know when you return to your loved one and feel overwhelmed with the reconnection. There are a variety of documentation log options. Check out one example of a [caregiver log](#) from the National Caregivers Library.

Review the log with your respite provider and discuss the types of notes you'd like to read in the miscellaneous section of the report.

Make sure that you also review the completed log with your loved one after each visit. Continuing to include your loved one in on the respite process demonstrates that you rely upon their eyes and ears when you are away. These conversations will also help provide the foundation for productive feedback that your respite provider should receive, helping the next session run smoother than the last.

Tips for asking follow-up questions of your loved one:

- Ask open-ended questions
- Be positive
- Have an open mind
- Offer support and encouragement
- Collaborate on solutions

Respite is for recharging your mind, body, and spirit.

SELF CHECK-IN

Take a moment to check-in to be sure you are getting what you need to stay healthy. Make sure a part of this check-in is taking note of any caregiver guilt that you may have. Here are a few great resources to help you do just that.

[Caregiving MetroWest.org](#) has developed a Caregiver [Weekly Check-Up](#). to help you take note of your health and where you should focus some attention to replenishing. Another weekly check-up list to take a look at is the [Iona Self-Assessment](#) provided by Iona Senior Services.

The [Family Caregiver Toolbox](#), provided by the Caregiver Action Network, is a great resource on different caregiving topics.

Addressing caregiver guilt, here are a few articles to do just that. [Eight Tips to Managing Caregiver Guilt by Dr. Vicki Rackner, MD](#) and [A Guide to Taking Care of Yourself by Family Caregiver Alliance](#).

Be kind to yourself and remember with each new journey are lessons learned that make the next one that much better.

The Idaho Caregiver Alliance wishes you a wonderful respite journey.

ABOUT THE IDAHO CAREGIVER ALLIANCE

The mission of the Idaho Caregiver Alliance is to advance the well-being of family caregivers by promoting collaboration that improves access to quality support and resources, including respite for caregivers across the lifespan.

If you would like to learn more about or become part of the Idaho Caregiver Alliance please check out our website at www.idahocaregiveralliance.com.

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